

Successful Adaptations for Learning to Use Touch Effectively

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A Parent's Perspective: What I want from my Daughter's Educational Team

by Patty Salcedo, M.A.

Shoshanah and our Family

My daughter just turned 19 years old. At age 16 she lost what little vision she had when her retina detached, leaving her totally blind. Shoshanah was born with only one eye and was quickly diagnosed with congenital glaucoma and macular degeneration in that eye. Shoshanah has a mild hearing impairment, cognitive delays, fine and gross motor problems (she uses a wheelchair), and speech/language delays. She has a seizure disorder that has intensified in adolescence.

Shoshanah loves to listen to music and her favorites include Puccini operas and Cat Stevens. She has recently learned to operate her CD player independently and search for favorite songs. She enjoys playing *Star Trek* games with action figures (Counselor Troi is her best friend). These make-believe friends allow her to think out loud and get her through lonely times. They also accompany her to her many medical appointments and seem to offer a source of real comfort—no "make believe" about it. Shoshanah communicates verbally. Although her language and articulation are poor, she loves to talk, sing, and listen to her favorite TV shows: *Star Trek* and *Jeopardy*.

Shoshanah loves people. Cheering the antics of friends and family is her favored role in group activities. She enjoys funny noises, walks to the park, and assisting her classmates. Shoshanah's teachers remark that she has never said anything negative about anyone, and in fact, enjoys almost everyone she meets. She speaks of her "girlfriends" and "her kids" and looks forward to school as the opportunity to help others. She attends a local high school where she is enrolled in a special day class for students with orthopedic impairments. She is integrated into general education one to two periods a day in courses such as ceramics and choir.

Shoshanah lives at home with both of her parents. Her beloved older sister is away at college. School vacations are a source of celebration when the whole family can be together. During the year, Shoshanah looks forward to weekly phone conversations with her sister, and occasionally dictates an email. Extended family lives in Southern California and chooses not to stay in close contact, although Shoshanah loves to talk with them on the telephone.

Tactile Strategies

Since the total loss of her vision three years ago, Shoshanah has become more

reliant on tactile strategies to interact with her world. It has taken much of the past three years to develop these strategies. At home, Shoshanah has learned to identify tactile landmarks as she regains the confidence to move about the house. She recognizes her bathroom, for example, by the linoleum floor and the throw rugs. She has memorized the position of her toothbrush holder and toothbrush. Independent toothbrushing is one of her goals, and the teacher credentialed in visual impairments (VI) has helped her locate the necessary items to brush her teeth and wash and dry her face using touch.

Learning to carry out activities of daily living using tactile strategies has become increasingly important. Shoshanah is learning to sort laundry. She is not yet able to make fine tactile discriminations, so she is working on differentiating socks by size. She enjoys helping out in the kitchen, and as she has been working on concepts of categorization, she now identifies a number of citrus fruits through texture, shape, size, and smell.

Previously, Shoshannah read numerous large print sight words. She has not been able to learn any braille, yet she still remembers the shape of print letters. We have worked with the teacher (VI) to develop a tactile labeling system for Shoshanah. We attach a magnetic letter to materials such as each of her music CDs. She can identify the beginning letter of the artist's name, and then locates the appropriate CD. For convenience, she is working towards recognition of flatter letters such as those produced from puffy paint. We are expanding the use of this identification system at home and at school, labeling more of Shoshanah's belongings.

Materials are stored in containers of different shapes, and Shoshanah has learned to associate the container with the contents. The containers are made of different materials (plastic, metal, wood, basketry) for added information and esthetic appeal.

The teacher (VI) developed a tactile version of the card game, "Go Fish," one of Shoshanah's favorites. She uses small foam shapes on a card rather than numbers, and she enjoys playing this game at school with a classmate. Her Friday afternoon card parties at school also include entertaining her friends. Shoshanah sets the table by using trays and placemats to establish her working area, and using the plate as a central point of reference. As a place setting is completed, it is moved aside to make room for another. In this way, Shoshanah does not need to move around the table, a difficult task.

Making the transition to a more tactile approach to the world has not been easy for Shoshanah. She learns slowly and she requires much repetition. She relies on her well-established routines and is hesitant to try new activities or methods of interaction. Many of her current favorite activities began with intensive specialized instruction and much cajoling.

Shoshanah has not demonstrated great sensitivity in her fingers. She has always struggled with fine motor tasks, and her delayed cognitive level challenges her ability to learn complex concepts. Braille, then, does not seem like an effective communication medium for Shoshanah. Rather, we work within the realm of what she can perceive, discriminate, associate, and enjoy.

The Educational Team

The educational team for Shoshanah is large. Her primary special education teacher holds a credential in orthopedic impairments. She is the contact for other team members. The teacher credentialed in visual impairment works with Shoshanah daily. She is responsible for helping Shoshanah develop compensatory learning and daily living skills as well as informing other team members of her learning style. The orientation and mobility instructor assists Shoshanah map her

world and locate the different activities in her day, both within and outside of her classroom. The speech and language pathologist works on Shoshanah's ability to be understood. The inclusion specialist helps design successful, integrated experiences on campus, and provides advocacy for Shoshanah's abilities and right to participate in typical teenage activities. The vocational specialist has helped to establish a work experience (Shoshanah much enjoys filling bags at the local food bank. She has also worked at the district's materials lab). Shoshanah receives occupational therapy to assist her with daily living skills and to address sensory integration goals. Until recently, Shoshanah has received services from the school audiologist, the behavior specialist, and the technology specialist.

My daughter's unique constellation of challenges and strengths does not suggest an educational placement that meets all of her needs. Finding an appropriate placement is difficult. Some are too generic and some focus solely on one disability. For example, she has been enrolled in a class for students primarily with orthopedic impairments. A team comprised of members with different expertise is needed across all of her educational settings. I work and hope for the following outcomes from the educational team:

1. A commitment to work together to develop and implement a cohesive plan for Shoshanah—not to address her individual disabilities in isolation. Working together includes supporting each other as team members. We as parents appreciate transdisciplinary thinking and the development of activities that support a successful school day and increased quality of life at home.

2. A commitment to work from Shoshanah's strength, abilities, and interests. This team is establishing the foundation for Shoshanah's adult life activities, which we would like to be meaningful and satisfying. We want others to enjoy her, and this requires structuring activities that encourage success.

3. A commitment to honest communication with us as parents and amongst other team members. We need information as to the successes or obstacles to IEP goals much more frequently than annually. We as a family can support school activities and Shoshanah's progress if we are informed. Similarly, team members need to seek and value each other's input.

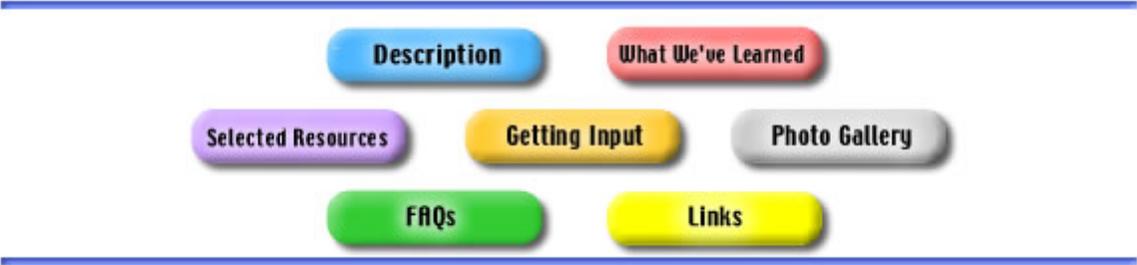
4. A willingness to try something new and give an idea ample time to succeed. Shoshanah does not learn quickly. Learning through touch and limited hearing takes time, and she must be provided much information and opportunities to experience.

5. Respect for our role as parents and for each other. We as parents do not want to mediate personnel conflicts, nor do we want educators squabbling for turf. We as parents do not want to be feared as angry advocates or dismissed as unrealistic or uninformed. We wish to be seen as individuals, and we expect team members to view each other similarly.

6. Integrity as professionals and team members. We sign the Individualized Education Program document in good faith that the goals and objectives will be addressed. As we expect obstacles, we also expect that they will be addressed so that the goals can be modified for success.

One of the biggest challenges for Shoshanah is the challenge to her educational team: to look at life from her perspective, to believe in her ability to learn, to think creatively, and to respect her as an individual. When I am able to let go of my

definitions of quality of life, and examine what Shoshanah truly enjoys, I am better able to assist her in creating her own quality of life.



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